DOCUMENT RESUME

ED 364 710 CE 065 221

AUTHOR Schmall, Vicki L.; Cleland, Marilyn
TITLE Helping Memory-Impaired Elders: A Guide for Caregivers. A Pacific Northwest Extension Publication. PNW 314.
INSTITUTION Idaho Univ., Moscow. Cooperative Extension Service.; Oregon State Univ., Corvallis. Cooperative Extension Service.; Washington State Univ., Pullman. Cooperative Extension Service.
PUB DATE Jul 88
NOTE 21p.
PUB TYPE Guides - General (050)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Adult Education; *Aging (Individuals); Alzheimers Disease; *Caregivers; *Coping; Extension Education; Frail Elderly; *Helping Relationship; Home Economics; *Memory; *Older Adults
IDENTIFIERS *Memory Deficits

ABSTRACT

This cooperative extension bulletin is designed to help family and professional caregivers understand dementia in later life and learn to cope more effectively with the changes resulting from a progressive dementing illness. The first three sections describe the differences between senility and dementia, causes of dementia, and adjustments that families of dementia patients must make. The next two sections present a series of self-care guidelines for caregivers and general guidelines. Included among the guidelines discussed are the following: learn about the disease, ask for and accept help, maintain meaningful relationships, take breaks from caregiving, understand and accept feelings as normal human responses, make realistic commitments, hope for the best while planning for the worst, join a support group, keep expectations realistic, be consistent, limit choices, use repetition, use memory aids, simplify tasks, encourage recognition rather than recall, make the environment safe, use reminiscence, reassure and praise, and maintain a sense of humor. A section on approaches to special problems examines these topics: driving, managing money, wandering, Sundowner's syndrome, catastrophic reactions, hallucinations and delusions, bathing and grooming, meals, incontinence, hiding and losing things, and communication. A summary and list of resources conclude the booklet. (MN)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 364 710

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it.

Minor changes have been made to improve reproduction quality.

Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

D Mac

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Helping Memory-Impaired Elders

A Guide for Caregivers

A Pacific Northwest Extension Publication
Oregon • Washington • Idaho
PNW 314 • Reprinted July 1988

CE065221

BEST COPY AVAILABLE

Contents

Senility versus dementia	3
Causes of dementia	4
The family's adjustments	4
Self-care for the caregiver	5
General guidelines	9
Approaches to special problems	13
Summary	20
Resources	20

Pacific Northwest cooperative Extension bulletins are joint publications of the three Pacific Northwest states—Oregon, Washington, and Idaho. Similar crops, climate, and topography create a natural geographic unit that crosses state lines. Since 1949 the PNW program has published more than 300 titles. Joint writing, editing, and production has prevented duplication of effort, broadened the availability of faculty specialists, and substantially reduced costs for the participating states.

This publication was prepared by Vicki L. Schmall, Extension gerontology specialist, Oregon State University, and Marilyn Cleland, R.N., caregiver education coordinator, Neurological Sciences Center, Good Samaritan Hospital, Portland, Oregon.

Published and distributed in furtherance of the Acts of Congress of May 8 and June 30, 1914, by the Oregon State University Extension Service, O. E. Smith, director; Washington State University Cooperative Extension, J. C. Engibous, interim director; the University of Idaho Cooperative Extension Service, H. R. Guenthner, director; and the U.S. Department of Agriculture cooperating. The three participating Extension Services offer educational programs, activities, and materials without regard to race, color, national origin, sex, or disability as required by Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, and Section 504 of the Rehabilitation Act of 1973. The Oregon State University Extension Service, Washington State University Cooperative Extension, and the University of Idaho Cooperative Extension Service are Equal Opportunity Employers. 50/50/50

Helping Memory-Impaired Elders

A Guide for Caregivers

This publication is designed to provide family and professional caregivers with an understanding of dementia in later life and ways to cope more effectively with the changes resulting from a progressive dementing illness.

In addition to general care and management guidelines, it outlines approaches for handling specific problems—driving, wandering, money management, catastrophic reactions, hallucinations, eating, incontinence, hiding of items, and communication.

Senility versus dementia

For several years Joe had known he was having memory problems. He compensated for his forgetfulness by writing himself notes of once-familiar names, telephone numbers, and things he had to do.

Sometimes he became annoyed when people tried to help by reminding him. He silently worried about becoming "senile." He was, after all, 64 years old.

Recently, Joe encountered a detour while driving home from the neighborhood grocery store. He arrived home two hours late. He had become lost three blocks from home. He felt frustrated and afraid, but he covered up by telling his worried wife that he ran into an old friend.

Joe's work suffered. His employer suggested an early retirement. Joe felt worthless. Growing old was depressing.

Joe mistakenly believed and accepted his problems as the inevitable result of aging. He is not alone.

Many people, including some health professionals, share this myth and label disoriented older adults as "senile."

Many people fear that aging leads to "senility" or loss of memory. Getting older does not necessarily mean losing one's intellectual abilities. Actually, the word *senility* has been used erroneously. It is derived from a Latin word which means "to grow old."

Dementia is the more appropriate word to describe significant progressive loss of mental abilities experienced by some older people.

Symptoms of dementia include impairment in thinking, learning, memory, and judgment; and changes in personality, mood, and behavior.

Dementia is the result of a disease process, and although it is more common with advancing age, it is not a normal part of growing older.

Benign Senescent Forgetfulness (BSF), or simple forgetfulness, is part of the normal aging process. It can be caused by stress, fatigue, grief, or an overload of information. It's not a sign of, nor does it lead to, dementia. The problem is usually with recall, not memory.

Elders concerned about their forgetfulness should ask themselves, "How did I know I forgot?" The answer: "Because I remembered later." In a dementing illness, these memories cannot be recalled because they have been erased from the mind.

Confusion and intellectual impairment sometimes can be caused by treatable illnesses, reactions to medications, drug intoxication, depression, poor nutrition, infections, and metabolic disorders such as a thyroid problem.

Over 100 reversible (treatable) conditions can mimic dementia. If left undiagnosed and untreated, they may become irreversible.

Causes of dementia

The onset and course of dementia depend on the particular disease causing it. The symptoms can vary widely, and no two afflicted persons follow precisely the same course or rate of progression.

Alzheimer's (Alz-hi-merz) disease accounts for 50 to 60 percent of dementia cases. In Alzheimer's disease, the nerve cells are destroyed throughout the cerebral cortex, the outer layer of the brain.

As the disease progresses, afflicted individuals lose more and more of their memory and other abilities. Eventually, they are not able to function independently. The time from onset to total disability may vary from 3 to 20 years.

A diagnosis of Alzheimer's disease is made by ruling out all other causes of the symptoms. As of 1984, there is still no way to be certain of a diagnosis of Alzheimer's disease without a brain biopsy or autopsy.

Currently, there is no known cure or prevention for Alzheimer's disease. Medical researchers, however, are making great strides in understanding the disease and helping the patient and family to function better.

Multi-infarct dementia (series of small strokes in the brain) is responsible for about 15 percent of dementia cases. These small strokes can happen months or years apart, but together they damage enough brain tissue to affect mental functioning.

Multi-infarct dementia progresses in a stepwise fashion—the person may lose some abilities with a small stroke and stay at that level of impairment until the next ministroke. The person may even appear to improve slightly for a time.

The symptoms experienced by the individual depend on the area of the brain that has been damaged. Some cases of multi-infarct dementia progress over time, but others do not.

The remaining cases of dementia are caused by a combination of Alzheimer's disease and multi-infarct dementia or one of several rare neurological diseases.

The family's adjustments

Not only the patient suffers from the effects of dementia—the family, too, is greatly affected. Coping with the changes and problems associated with a progressive dementing illness places tremendous stress on families.

The "loss of the mind" is difficult for both the patient and the family to accept. As dementia progresses, patients tend to lose insight into their condition.

For the family, however, losing the person they have always known, although he or she is still physically present, can be very painful. Family members have said:

> "It's like looking after a six-foot two-year-old who is accustomed to doing what he wants to do."

> "It's very, very hard to watch someone you love die—very, very slowly. We go through many emotions—hurt, anger (at them, at ourselves), frustration, bitterness. We feel helpless!"

> "It's like a funeral that never ends."

Denial is common early in the disease. The impaired person usually looks healthy, can talk about familiar topics, and sometimes even seems to improve. Many changes are subtle, and early in the disease patients often are adept at covering up memory loss.

They may write themselves "memory notes," blame others ("Who took my wallet?"), or attribute memory loss to stress or other pressures.

Family members may have attributed the patient's inability to carry out tasks to laziness

or stubbornness, and this led to arguments. When the disease is recognized, strong guilt feelings may be experienced. Family members may blame themselves for not being aware of the changes earlier.

Dementia also results in a gradual shift of tasks and responsibilities from the patient to the caregiver. These added responsibilities can be overwhelming.

Social and emotional isolation occurs for many caregivers. The caregiver may not be able to leave the patient alone at home. The patient may become easily upset in public, may be unable to tolerate being around people, and/or may lose social graces.

Friends and family may stop visiting if they do not understand the disease or if they find it difficult to see the deterioration in the person or to accept the behavior and personality changes.

Caregivers comment:

"To go out is scary, not knowing what I'll find when I get back. My last night away was four years ago."

"During the five years of caring for my husband, I only left home to purchase food and medications. I prayed nothing would happen while I was away."

"I feel like a prisoner in my own home."

"Usually, we just stay at home because I don't know how he will act. If we have dinner with friends, he may refuse to eat and want to go home, so our social life is negligible."

"I need my friends more now than ever, but so many no longer visit or call. I know it's painful for them, too."

For the healthy spouse, there often is a loss of a companion, sex partner, and someone with whom to share life's joys and problems.

Caregivers must be realistic about what they can do. Eventually, the patient may need round-the-clock care and supervision. No person can provide total care without help. Those who try usually become physically and emotionally exhausted.

Self-care for the caregiver

With a dementing illness, caregivers must take care of themselves as well as the patient. The following are self-care guidelines for the caregiver.

Learn about the disease. If a diagnosis of a dementing illness is made, everyone involved in the support and care of the patient benefits from information about the disease.

Learning about the disease—what can be expected as the disease progresses and how to deal with behavioral changes—enables families to better understand and accept the patient, plan for the future, and set realistic expectations. Unrealistic expectations can compound problems by increasing anxiety and agitation in the patient and stress for the caregiver.

Don't hide—this is a disease, not a crime. Some families are inclined to hide their family member's illness. Although explaining the disease to others may be difficult, it helps family, friends, and neighbors to understand the behavior of the patient and the stress of caregiving. People need to know:

Dementia causes the brain to fail, just as diseases of the heart and kidneys cause those organs to fail.

The disorder is not contagious.

People afflicted by the disease are not "insane" or "crazy."

The disease causes a gradual deterioration of the mind. This means that patients increasingly are unable to remember, use good judgment, control their behavior, and perform seemingly simple tasks like dressing themselves.

Ask for and accept help. Caregivers should not try to "go it alone." Look for sources of help and information inside and outside your family. Let family and friends know how they can help.

Be specific with your request. And be appreciative. Don't be a martyr—this will likely "turn off" caring helpers. Realize that some people will help more than others.

Contact county and state health and/or social service agencies that serve older people, adult community or senior centers, local offices of Social Security and the Veterans Administration (if the impaired person served in the military).

Homemaker service agencies can provide help with personal care and housekeeping chores. Meal delivery, transportation, and shopping services may also be available.

In addition, most states have a chapter of the Alzheimer's Disease and Related Disorders Association. They offer information and support for only a telephone call.

Maintain meaningful relationships. Build and fortify your relationships early in the disease. Family and friends can be a source of great comfort, help, and pleasure.

Caregivers who take time away from their responsibilities to meet their own needs for companionship and recreation generally feel less trapped and less isolated, and they are better able to care for the impaired person.

Take a break from caregiving. Regular breaks from caregiving are essential. The most common reasons for nursing home placement are that the caregiver simply could not manage alone any longer or became ill.

A chance to get away allows the caregiver to rest physically and emotionally. It's as important to health as diet and exercise—and *it's not selfish!* We call this chance to get away "respite"—and it benefits the impaired person as well.

Consider family members, friends, neighbors, fraternal and church affiliations, or college and nursing students for assistance and a break from caregiving.

In some communities, adult day care and/or inhome respite care are available. Some nursing homes also offer adult day care and short stays for elders, so caregivers can take a short break—or a needed vacation.

Taking a break generally requires frankness. Remember, family members not directly involved in care may not realize the demands of caregiving or may fear the responsibility.

Caregivers should give the following information to respite care providers:

Emergency telephone numbers, including the name and number of the doctor, preferred hospital and ambulance service, nearest relative or friend to contact, local police and fire departments, or an emergency dispatch number (if there is one).

How to reach the caregiver.

Estimated time of the caregiver's return.

Special instructions for relating to and caring for the impaired elder and managing difficult behavior—for example, "When Fred picks at his clothes, it may mean he needs to use the bathroom."

It's very important to be honest about any problems. Sooner or later, a substitute care provider may have to confront difficult behavior.

A brief note reminding the memory-impaired person of the caregiver's whereabouts and hour of return may reduce questioning and anxiety. This information is also important when the person is left in an unfamiliar place for a short time.

Understand and accept feelings as normal human responses. Families and caregivers dealing with a dementing illness experience many mixed and powerful feelings—grief, anger, sadness, embarrassment, shame, guilt.

Remember that feelings are not deeds—good or bad, right or wrong. They are human responses that everyone feels, expecially when dealing with the stress of a chronic, progressive illness.

Anger is a normal response to frustration. Caregivers often feel trapped. They may feel angry at God that this has happened, at the strange and embarrassing behaviors of the memory-impaired, at others who offer advice but don't help.

No matter how much a caregiver loves the patient, the behavior of the memory-impaired person can be exhausting and difficult to tolerate. Caregivers, too, have emotional limitations—and they need opportunities to express their anger, frustration, and hurt.

If you get angry, that's human. Acknowledge your right to feel angry; then do something constructive about it. It's important to find someone who is willing to listen and understand such feelings.

Guilt feelings are common. Caregivers may feel guilty about their anger, about long-forgotten misdeeds of the past, about death wishes for the memory-impaired, about mistakes or outbursts in dealing with the person.

Caregivers must forgive themselves and forget the incidents. Consider that the impaired person has already forgotten.

Divided loyalties are commonly experienced by adult sons and daughters who are caregivers. Competing demands from younger children, elderly parents-in-law, a spouse, and a job can overwhelm the most devoted and dedicated caregiver. The personal needs of the caregiver may be overlooked or ignored.

If it's not possible to balance these responsibilities, set priorities. The needs of children and the survival of family unity should come first. Professional help may be needed to sort through complex and emotionally charged problems and adjustments.

Make realistic commitments. Nearly everyone has made an emotionally-laden promise that is based on an unknown future. One of the most common is a promise never to place a family member in a nursing home.

Unforeseen circumstances may mean it's not possible to keep some promises. Recognize

that the conditions under which such promises were made were quite different from the current situation you face.

A realistic commitment doesn't include words like "always," "never," or "forever." It's a pledge to do something, but not everything regardless of what happens.

Particularly important is not to let old promises or guilt guide decisions. They reduce objectivity and your ability to make the best choice.

You need to consider what is best for you and your family as well as for your memory-impaired family member. It's important not to sacrifice your own physical and emotional health.

Hope for the best. Plan for the worst. Caregivers need to look at a broad range of questions in planning for the future.

What are the legal implications of progressive mental impairment? What should be done, and when?

Where are important documents and valuables located?

How can family, friends, and community services help with care?

What arrangements can be made for respite?

What should be done in an emergency?

What are the alternatives to nursing home care?

Under what conditions would nursing home placement be the best decision? What does this mean in terms of economic and personal concerns?

A time may come when nursing home care is best for everyone. This is often a very difficult decision. For this reason, some families hesitate to consider, investigate, or plan ahead for this possibility until a crisis occurs—change in the memory-impaired elder's health, or unexpected illness or death of the caregiver.

Being informed and prepared helps avoid crisis decisionmaking and the making of unsatisfactory choices.

The Alzheimer's Disease and Related Disorders Association (ADRDA) offers these guidelines for deciding about placing a memory-impaired person in a nursing home: If the memory-impaired person wanders, presents a danger to self or others, is unable to care for self in the most basic ways, and frequently interrupts another's sleep, placement is probably desirable.

Join a support group. Family support groups can provide a tremendous source of information and understanding. Mutual sharing between people who are coping with a family member with a dementing illness reduces feelings of isolation and guilt.

Families have set up local volunteer organizations in many areas of the country. They provide support and education, and they promote advocacy, legislative action, and research.

For more information, write the National Alzheimer's Disease and Related Disorders Association (ADRDA), 70 East Lake Street, Chicago, Illinois 60601.

The national association also publishes a quarterly newsletter that reports on current research about dementing illnesses and offers practical suggestions for coping.

For information about the nearest support group in Oregon, contact the Alzheimer's Disease and Related Disorders Association of Columbia/Willamette, Good Samaritan Hospital, 1040 NW 22nd Avenue, Portland, Oregon 97210; phone (503) 229-7115.

General guidelines

The amount of care, supervision, and help with tasks needed by a memory-impaired person will depend upon the extent of the disease. Managing a person with progressive memory loss is not easy, but patience, understanding, and skills will help.

The following guidelines may reduce anxiety and improve the quality of life for both the patient and the family.

Keep expectations realistic. Realistic expectations will reduce frustration for both you and the patient. Know what you can expect from the memory-impaired person who has a progressive dementing illness.

Psychological testing may be helpful. It can provide a realistic measure of how much to expect from the patient and identify the cognitive abilities still intact.

Your physician may be able to direct you to professionals who can best provide such testing.

Maintain a calm atmosphere. Being rushed or being around a lot of activity tends to confuse and frighten the memory-impaired. Even small amounts of excitement can cause agitation.

Avoid confronting or overloading the individual with stimulating experiences. Alternate activity with quiet times. Plan simple family events or outings after quiet days or on otherwise quiet days.

Keep your voice calm and reassuring. The tone of your voice and the feelings expressed are as important as your words. In fact, the person will tend to respond more to the *tone* of your message rather than to its content.

Arguing and scolding usually will only cause the person to overreact. Remember: The person's behavior is a result of the *disease*, not stubbornness or willfulness.

Be consistent. Avoid changes and surprises. Persons with a dementing illness generally do best in familiar, well-organized environments and with consistent routines. They have difficulty coping with change—even seemingly minor changes like rearranging the bedroom furniture.

Keep household furnishings and objects in the same place at all times. Do what you say you are going to do. Do things the same way at the same time each day. For example, if you go on walks, go out the same door, at the same time, and use the same route. A consistent routine and environment helps the person feel secure and calm.

When you must make changes, prepare and support the person but avoid lengthy explanations. Take care when you plan a trip or vacation. Some persons become agitated and more confused in strange, unfamiliar surroundings.

Establish early a schedule of daily activities based on the patient's lifelong patterns, if possible. Plan more difficult tasks for the person's best time of day. Keep in mind that the memory-impaired tend to have short attention spans—30 minutes or less.

Post the schedule. Not only will this help the person who can still understand the written word, but it will also make it easier for anyone who comes into the home to assist the person.

Limit choices. Limiting the choices the person has to make reduces confusion. For example, remove seldom worn and out-of-season clothing from the closet. Limit the number of food choices and put out only the utensil(s) the person will need at mealtime.

Use repetition. Memory-impaired people need frequent, patient reminders. They simply may not remember what they are told because the brain no longer has the ability to retain information. Be prepared to repeat the same instructions daily, sometimes several times in succession.

The person may remember some tasks and information from repetition. Don't assume the person will forget promises you have made, places you have said you will take him or her, etc.

Remind with brief, simple statements; avoid lengthy explanations. When repeating, do not remind the person that you said it before. Don't use phrases like "Don't you remember . . . I told you yesterday" or "I've already told you four times."

The fifth time the person asks the same question within a short time can try anyone's patience, but it may help to understand that each time the question is asked is like the first time to the person with a dementing illness. Remember: The person may no longer be able to remember answers given to questions or that he or she even asked the question before.

Sometimes reassuring the person will reduce repetitive questions. Simple written reminders also may aid a failing memory, particularly if the caregiver uses them early in a progressive dementing illness.

Use memory aids. In early or moderate cases of memory impairment, memory aids can be helpful in promoting better orientation. Signs, clocks, calendars, seasonal decorations, and a schedule of the day's activities reinforce memory.

Give cues. For example, put labels on drawers, cupboards, appliances, and doors. When the person can no longer comprehend the written word, replace word labels with pictures. Mark off days on a calendar with a large felt pen so the person will see the current date.

Autographed photographs may help the person to remember family members and close friends. However, expect fluctuations in the person's ability to recognize people, even close family members. Don't take it personally when you are not recognized.

You may find it helpful to instruct family and friends that not being able to recongize them is a result of the disease. It may help people to know that some individuals deteriorate to the point where they don't even recognize themselves when they look in the mirror.

Simplify tasks. Tasks that previously were easy for the person may become too difficult. Reevaluate skills when the person becomes frustrated by a task or refuses to cooperate.

Breaking down complex tasks into simple steps and giving the person step-by-step instructions may enable him or her to continue to do some tasks. For example, the person may be able to partially set the table as long as the items are dealt with one at a time.

Demonstrating each step also may help—for example, brushing your teeth at the same time as the patient. Occasionally, memory-impaired who are helped with the first step of a familiar activity can then complete the activity. For example, when you assist the person with one sock, the person might be able to put on the other sock and (perhaps) even the shoes.

Think of parts of previously enjoyed activities that the person can still do. For example, the individual who enjoyed cooking (but for whom cooking is now too complex) may be able to mix batter or tear lettuce for a salad.

The former gardener may find satisfaction in raking the yard or watering plants.

Encourage recognition rather than recall. It's easier to recognize rather than to recall information. Limit the demands for recall of facts, names, and schedules.

For example, post a schedule of the day's activities. Name events and give the names of family members and friends who visit.

Say to a person who has difficulty remembering you, "I'm Jane, your daughter. I'm here to visit with you." Avoid saying "Who am I?" when the person can no longer remember who you are. Such questions generally are too taxing for the person and increase agitation.

Make the environment safe. Safety is a major concern in activities and the environment. Don't expect the person with dementia to take responsibility for his/her own safety.

Even a mildly impaired person may have lost the judgment needed to avoid accidents. Family members continually need to be aware of sources of danger.

Three potentially dangerous activities are smoking, cooking, and driving. Other potential danger points are high windows, stairs, swimming pools, power tools, appliances, knives, hot water, matches, cigarette lighters, firearms, poisons, and plants.

Memory-impaired persons sometimes forget they are smoking or forget to put a cigarette out. If possible, encourage the person to give up smoking. Otherwise, supervise the smoking. Keep matches and other smoking materials out of reach.

Patients may turn on the stove and forget they have done so or put flammable materials in the oven. Removing knobs from the stove may solve the problem. Or remove the fuse or open the circuit breaker when you're not cooking.

If you have questions about how to make a stove inoperative, consult your utility company.

Tap water can be dangerous. Lower the temperature setting of your hot water to prevent burns. Check the temperature and depth of bath water before the patient enters.

Install grab bars in the bathtub and shower and by the toilet. Use a rubber mat or no-skid decals on the bottom of the bathtub to prevent falls. Don't use bath oils that make the tub slippery.

Lock up potentially dangerous items. These include medications, firearms, power tools, small appliances, knives and other sharp objects, razor blades, alcohol, and cleaning supplies.

Patients often do not know the difference between what is and is not edible. Make sure that poisonous items like cleaning fluids are not accessible.

Remove items that resemble food, such as plastic fruit or rocks in a jar that they might mistake for candy.

Observe when the person begins putting inappropriate items in his or her mouth. If this occurs, remove things like plants, buttons, small knickknacks, and other items that might be swallowed.

Remove locks on bedroom and bathroom doors to avoid the person getting accidentally locked in a room. Lock windows or limit the amount they can be opened so the person cannot climb out.

Install locks on outside doors to prevent the wanderer from leaving unnoticed. A hard-to-reach lock on the kitchen door also may be helpful.

Awakening in the dark can be disorienting. Night lights in the bedroom, hallway, and bathroom and/or a strip of glow-in-the-dark tape from bedroom to bathroom increase nighttime safety and help orient the person.

Be sure that stairs are made safe to prevent falls. Remove any objects the person might trip over, such as scatter rugs, footstools, and electrical cords.

Because memory-impaired people are at greater risk for accidents, knowing first aid procedures can be helpful. Contact the Red Cross about classes.

Use reminiscence. Reminiscing about the past may help the person become involved in what he/she can remember. It can also build self-esteem since the past generally was a time when the person felt independent, productive, and contributing to the lives of others.

People who seem to have little memory often respond to discussions about significant personal experiences (weddings, births of children, hobbies) in their past and unique historical events (the Depression).

Old photographs, special holidays, and familiar songs often evoke memories and reminiscing.

Approach the person slowly and in front. Moving quickly, pushing or pulling the person, and approaching from behind may startle the person and stimulate agitated behavior and resistance.

Treat the person as an adult. The memory-impaired have feelings and don't like to be treated as children. When they're treated like children, they're more likely to respond with childlike behavior.

Avoid "talking down" to or "babying" the person. Maintain an attitude of respect and dignity and let the person be as independent as possible, even if tasks are not done as well as you would like.

Reassure and praise. Persons with dementia also need a feeling of success. Provide praise for tasks accomplished. Tasks that are relatively easy for the healthy person may be difficult for the memory-impaired, such as cooking, bathing, dressing, and remembering to go to the bathroom.

Throwing and catching a ball or singing old familiar songs are simple, concrete activities that give some memory-impaired persons a sense of accomplishment and fun. Small accomplishments amount to tremendous victories for persons who have problems with memory.

Maintain a sense of humor. Families find a sense of humor especially helpful in dealing with trying situations—finding garden tools in the refrigerator or finding their family member has removed all clothing to use the toilet after just struggling to dress the person.

Such behavior may be easier to accept if you realize that the person does not do these irritating behaviors on purpose. Seemingly bizarre, rude, and stubborn behavior is beyond the control of the person with a dementing illness.

Try to have a good laugh occasionally. Laughter and humor have positive effects on physical and mental health.

Approaches to special problems

In addition to the general care and management guidelines, the following approaches to specific problems may be helpful.

Driving. Families have a responsibility to act when the memory-impaired person no longer drives safely. Judgment, memory of the rules of the road, and reaction time may all be impaired early. Getting lost and near-misses in traffic are clues to problems.

Don't rely on daylight hours and familiar routes to delay this difficult decision. Detours, accidents, children, and animals can surprise the driver. Remember that the impaired person generally doesn't cope well with changes.

If possible, involve the person in the decision. Be gentle but firm. Giving up driving will be accepted by some and strongly resisted by others.

Giving up driving is difficult for many people because a car represents freedom, independence, and mobility. Feelings of frustration or anger may be directed at the caregiver.

Assure the person that he/she will stay mobile and that you will arrange transportation and regular outings.

The family physician can help by advising the State Department of Motor Vehicles, in writing, that for reasons of health the person should no longer be licensed to drive. Patients often will stop driving on the orders of their physician. A written prescription from the doctor stating simply "No driving" may remind the impaired person and divert blame away from the family.

If necessary, hide car keys or disable the car by removing the distributor cap. A service station attendant can demonstrate how to do this.

Managing money. Problems balancing a checkbook are common and an early sign of intellectual decline. Forgetting to pay bills and squandering or hiding cash are also early symptoms. Eventually, someone else must take over the person's financial matters.

Take care of financial and legal planning *early* to guarantee a safe financial future for both the impaired person and for yourself as the caregiver. This may include obtaining conservatorship and/or guardianship.

Consult an attorney for legal advice. There are laws that protect the impaired, and they vary from state to state. Banks offer services and information that may be useful.

Giving up control over money is often difficult because it means another loss of responsibility, freedom, and independence. The family may be accused of stealing.

Recognize the person's sense of loss and inability to comprehend the reality of the situation. Giving the impaired person small amounts of spending money may help.

Talk to managers of stores or restaurants the impaired person is likely to visit. Explain the nature of the person's problem. Make arrangements to pay for or return unwanted items the impaired may have been unable to pay for, or forgot to pay for.

Remember: When police are called, they respond to the apparent act. They do not make judgments about intent. With information about the impaired person, storeowners often will be very helpful.

Wandering. Wandering is common and potentially dangerous. Traffic, weather, water, crime, missed medications, and exhaustion put the wanderer at risk.

The wanderer does not necessarily realize he or she is lost, may not remember where home is, and may not think of (or be able to use) a telephone.

Look for possible reasons for wandering behavior. Did the person previously enjoy walking and outdoor activities or use walking to reduce stress in his/her life? Is the person bored?

Is there somewhere the person wants to go or something the person is searching for? Was the person overstimulated by too much activity or noise in the home? Was the environment changed at home, or is the person in a new environment?

Does the person seem to be searching for some satisfaction? Calling out "I want to go home" or "Where is my mother?" may indicate a search for security.

Is the wandering directed toward a goal? Commenting on the need to perform a task or gesturing as if cleaning or performing a task may indicate a need to do something or be busy.

Is there a pattern to the wandering behavior? The wandering may seem to have no specific cause other than being part of the disease process.

Some wandering behavior stems from the need to exercise. Wandering may be reduced by taking the person on frequent walks or providing other exercise such as raking leaves or sweeping the driveway. Regular exercise also can relieve tension and help the person sleep better.

A high fence with locked gates may allow the person to freely wander and exercise outdoors. This may be particularly important to the person who spent considerable time outdoors before the illness.

Approach a wanderer slowly and calmly. Offer reassurance. Walk with the person a short distance in the direction he or she is walking. To hurriedly move the person or scold will generally make the person more agitated and confused.

If wandering is the result of stress, physical force or restraint usually will only increase the person's agitation. Use restraints only as a last resort.

Before using a restraint, discuss it with the doctor or other knowledgeable professional. Medication may help to lessen wandering behavior.

Logic and reasoning generally will not be understood. Memory-impaired people who are restless and wander can often be distracted by directing them to an enjoyed activity.

Alert neighbors and local merchants to the memory-impaired person's problems and ask them to contact you if they see the person leaving the area.

Have the patient wear an identification or medical-alert bracelet that gives the person's name, address, and telephone number and includes the phrase "Memory-impaired" or "Brain-impaired." Giving the diagnosis, such as "Alzheimer's Disease" or "Multi-infarct dementia," may not be as helpful because strangers finding the impaired person may not know what these terms mean.Simpler and more direct language helps others understand and deal more effectively with the wanderer.

Preventive measures include installing locks at the top or bottom of doors where the impaired person may not look, warning bells that jingle when outside doors are opened, or dead-bolt locks that you can lock on the inside with a key.

A room with an expansion safety gate across the open door (often used for small children) may provide an area where the

impaired can pace and explore safely. However, if the person is a "climber," such a gate could be hazardous.

Never leave the person alone in a parked car. He or she may wander away or cause an accident by starting the ignition or releasing the brake. Prevent the person from opening the door of a moving car by locking doors and using seat belts.

Wandering frequently occurs at night and may be the result of disorientation. Nighttime wandering also can be a sign of congestive heart failure. A medical checkup may be indicated.

Wandering at night can be particularly disruptive to the caregiver's sleep—and to the caregiver's physical and emotional well-being. Keeping the person awake and active during the day generally promotes better sleep at night.

If medication you give during the day to control behavior is making the person sleepy, talk with the doctor about changing the medicine, or the time it is given, to reduce daytime drowsiness and encourage sleep at night.

Make sure the person empties his or her bladder before going to bed.

The quietness and darkness of a home at night may also cause increased restlessness. Using a night light or playing the radio softly may help reduce wandering and confusion on wakening.

Sundowner's Syndrome. Individuals with a progressive dementing illness sometimes have more behavioral problems in the late afternoon and evening—hence, the name *Sundowner's Syndrome.*

No one knows the cause. It may be that the changes in the environment as darkness approaches are confusing to the person. Keeping the house well-lit at this time may help.

Or this may happen because the stimulating effects of sights, sounds, and activities have accumulated over the course of the day. By evening, the person has less ability left to cope with the surroundings.

It helps to remember that behavior does not occur in a vacuum. Evaluate the person's day. It may help to alternate activity (including dressing, meals, etc.) with quiet time.

Include a 30-minute rest period each morning and afternoon. Reduce all noise and distractions during this time (soft music may be the exception).

If the behavior occurs in the evening after a trip to a favorite restaurant, friend or family member's home, senior center, or vacation spot, it may mean the person can't cope with the activity any longer. Be prepared to gear down.

Catastrophic reactions. Memory-impaired elders sometimes overreact when a request, task, or situation overwhelms their thinking ability. Stubbornness, pacing, wandering, and weeping are common reactions.

Rapidly changing mood, anger, and violent striking out may also occur. It may seem childish to the caregiver for the person to become upset "over nothing." Aggressive behavior can be frightening.

Look for clues about what may be upsetting the person. Was the reaction the result of mounting frustration? Overstimulation? Misinterpretation of requests, events, or activities? Inability to perform a task? Fatigue?

A reaction can be triggered by being asked to think of several things at once; small mishaps; strange noises, people, and places; a confusing, unpredictable environment; and scolding and arguing. Signs of an impending outburst may be refusals, restlessness, and blushing.

You can often avoid catastrophic reactions by simplifying a task, a request, or the environment. After minor mishaps, allow time for the person to calm down.

It may work to ignore the behavior, leave the room, and let the person be alone if he/she is acting out and there's no risk of injury. Otherwise, calmly remove the person from the stressful situation.

Most memory-impaired persons are easily distracted. Use this to your advantage to divert the person from the situation. Distract with a favorite treat or activity.

Do something familiar with the person, like having a glass of juice or going for a walk. Soft music, holding hands, and rocking may help calm the person. Spending time with an uninvolved person also may help.

Avoid explanations, arguments, or restraining the person. Usually, these will only make the person more confused, angry, or combative. Recognize that feelings of distress may linger after the person has forgotten the situation.

And remember that the behavior is beyond the person's control—and can't always be prevented by the most experienced caregiver.

Sometimes, increased agitation and irritability are the result of internal discomfort—for example, pain or constipation—and the person isn't able to put this discomfort into words.

Any sudden deterioration in functioning or behavior may be a warning signal of a fall or illness. Check with the patient's doctor.

It's important to correct even minor physical and medical problems, because correction of such problems often improves the person's functioning.

If the person becomes aggressive and violent, get several people, if possible, to stand around him or her, but out of reach. The person may calm down when his or her actions seem futile.

If you are alone and your safety is in jeopardy, don't hesitate to leave and call for help. Call the nearest hospital and tell ambulance personnel that restraints may be necessary.

The physician may order a tranquilizer. If there is no hospital in your community, call the police. Give them information about the situation. Explain that the person cannot help his or her behavior, but that the behavior is getting out of control and you need help.

Seek professional help about reducing the occurrence of future violent episodes and about coping with them if they do occur.

Hallucinations and delusions. Persons with a dementing illness may see or hear things that exist only in their minds. For example, one person kept seeing a cow on top of the neighbor's house. Another saw rats running under her bed. Such hallucinations can be disturbing and a source of intense fear.

Persons may also express beliefs that things have been stolen or that someone is going to harm them. These delusions can make the impaired fearful and resistant to all attempts at care and help.

Respond calmly to what the person is *feeling*. Remember that the impaired person's experiences and beliefs are based on his or her reality.

Attempts to confront, argue,and reason will usually make matters worse. The person can't stop the hallucinations just because they're illogical or unreal to you.

Knowing that the fears and behaviors are caused by the disease may make it easier to understand and cope with them. It often helps to touch the person gently and offer reassurance that you will see that things are all right. Some caregivers choose to ignore the behavior if the impaired person is not upset and has forgotten the situation. Again, it may help to distract the individual.

Bathing and grooming. Most people feel and act better when they are well-groomed. A checklist of activities—brush teeth, wash face, shave, comb hair, etc.—placed by the bathroom mirror will help some people early in the disease with grooming activities.

However, as memory loss progresses, some individuals resist bathing and changing clothes. Reminding the person about the necessity of these activities and using simple explanations may work.

For some people, tasks will need to be broken down into small steps, giving the person step-by-step instructions such as "unbutton your shirt," "take off your shirt," etc.

Bathing instructions written by a physician on a prescription pad, "bathe twice weekly," may help to persuade the resisting person to bathe. Try to avoid arguing as to whether a bath or shower is needed.

For the memory-impaired person, bathing may be frightening. The person may not be able to understand that someone undressing her is being helpful and not trying to harm her.

Water rushing out the pipe, going down the drain, or hitting against her body may be frightening. Remember: The person's brain may no longer process information accurately.

Bathing and grooming can be hard work. There are many steps required to take a bath and get dressed. The person may no longer be able to remember these steps or to do them in the right sequence.

You may need to lower your expectations about frequency of bathing when it becomes a hassle for both you and your patient. A sponge bath may be the best alternative. If the bathroom is warm and a calm atmosphere is created, the person may be more likely to cooperate.

Some families have found it helpful to fill the tub with 3 to 4 inches of water before the person enters the bathroom, to use a shower chair for both baths and showers, to install grab bars, to use a shower head on a flexible hose, and to play soft music.

Bathing is a private activity, and for some people it can be embarrassing to receive assistance. Allow the person to do as much as possible for himself/herself. Most importantly, never leave the person alone in the bathtub or shower.

If possible, try to maintain the person's lifelong routine. For example, if the person took a shower before breakfast, try to follow this habit. Simplify bathing and dressing. You can encourage dressing by laying out clothes in their order of use. When necessary, show the person what to do.

Use clothes that can be put on and taken off easily and that help the person to dress independently. You can replace clothing with buttons, hooks, snaps, ties, and zippers with slipover and slip-on shirts, skirts, pants, and shoes. This also means fidgeting fingers can't unzip or unbutton clothing in public.

Wash-and-wear clothing provides the easiest care. Don't argue if the person wants to wear the same clothing every day or insists on sleeping with a hat on. This is not harmful. If the person prefers to wear only one outfit, perhaps you can make life easier by buying another one just like it.

Mealtime. If you go out to eat, don't expect the memory-impaired person to be able to order. Small, quiet, and familiar restaurants are preferable to large, noisy, dimly lit places.

Keep menus familiar. Sometimes the impaired person will eat only one food several times a day or develop specific likes and dislikes. Accept the behavior if it doesn't interfere with overall nutrition and dietary restrictions. It's better for a person to eat what he or she wants than not to eat at all.

However, if the person shouldn't eat certain foods because of an illness like diabetes or high blood pressure, put a lock on the refrigerator door and cupboards.

Some persons forget to eat. Others forget that they have eaten—and want to eat constantly. Setting out a small tray of nutritious snacks or serving less food more often is sometimes a satisfactory solution.

With increasing brain deterioration, persons frequently lose their coordination and table manners. They may lose the ability to use a knife and fork or to make proper food choices. For example, they might put gravy on salad instead of on potatoes.

Remove unnecessary utensils, condiments, foods, etc. The person may become confused if he or she has to choose between several utensils or foods. Sometimes it helps to serve only one food at a time.

Prepare the person's plate. Cut food into small pieces. Use finger foods when the person can no longer use utensils. Serve soup in a cup if the person has difficulty handling a spoon. Use a plastic cloth on the table, spill-proof containers, and smocks with the bottom edge turned up into a big pocket to catch crumbs.

Avoid foods the person may not chew thoroughly, such as nuts, popcorn, and raw carrots. Liquids and solids offered together may be confusing—the impaired may not know whether to chew or to swallow. Because the person can lose the ability to judge temperatures, serve foods and drinks lukewarm, *not hot.*

Consistency at mealtimes and a calm atmosphere without distractions may help the person to function best. Set the table in the same way, serve meals at the same time each day, and seat the person at the same place.

A person who has difficulty swallowing should sit up straight with the head tilted forward slightly—never back—and remain seated at least 15 minutes after eating. If your patient begins stuffing too much food into his or her mouth, remind him/her to swallow. Don't allow the person to lie down or walk around with food in his/her mouth.

Foods of a soft, even consistency (like purees) are easiest to swallow. Thin liquids (water, apple juice, coffee) are the hardest to swallow.

Learn the Heimlich method from a medical professional or the Red Cross. It can save the life of a choking person.

If you have to spoon-feed the person, it may help to talk with a nurse or speech pathologist who specializes in swallowing about the best procedure to follow. You may need to remind the person to swallow *after each bite.*

Contact the doctor if the patient stops eating or begins losing weight. These may be symptoms of a complicating disease.

Incontinence. As the disease progresses, loss of bladder and bowel control becomes more common. At first, this may occur only occasionally or during sleep.

Later, the person may not be able to respond to the body's signal to void or to remember the acceptable places and ways to eliminate bodily wastes. A man, for example, may urinate in the closet or wastebasket, or on the sidewalk in town.

Incontinence also may be caused by infection or other medical problems; therefore, check with your doctor when incontinence begins.

Establish a regular bathroom routine. This often decreases problems with elimination. You may need to remind the person every 2 or 3 hours, on rising in the morning, after meals, and before bedtime to go to the bathroom.

Take the person to the bathroom at the time of day he or she usually has a bowel movement. Observe the person's behavior for cues. For example, sudden restlessness or picking at his or her clothes may indicate a need to go to the bathroom.

Try to limit fluid intake after the evening meal. Getting the patient up once during the night or placing a commode or urinal bottle near the bed may help prevent accidents. Again, using night lights may help increase the person's orientation and ability to find the bathroom.

When a regular toileting schedule does not work, use incontinent aids. Special clothing with disposable pads, adult diapers, protective bedding, and disposable bed pads are

available from surgical supply houses and some drug stores. Watch for signs of redness and irritation on the skin.

Consult the physician or a nurse for additional aids available for urinal and fecal incontinence.

Hiding and losing things. Patients sometimes lose things, hide objects, or put them in safe but forgotten places. They may not return items to their customary places. Remain calm if the person loses or hides things. Keep important and valued items locked up. Reduce hiding places by locking closets, cupboards, and rooms the person doesn't use.

Hide a spare set of household and car keys in case your set disappears. Look for lost items in dresser drawers, boxes, coat pockets, shoes, and wastebaskets and under cushions and mattresses.

Check garbage cans before emptying if these become hiding places.

Communication. The ability to communicate with a person who has a dementing illness changes with the progression of the disease.

In the early stages of progressive memory loss, communication often isn't difficult, although the person may have problems finding the correct word, especially nouns. Language may be punctuated with indefinite words like "thing," "this," "that," and "there."

As the disease progresses, communication becomes increasingly difficult. The person gradually loses the ability to understand and use speech. As a result, he or she may not be able to understand instructions or report physical needs or discomfort to caregivers.

If taking a message confuses the person, disconnect the telephone when you're out or unable to answer it yourself. Or you could install a telephone recorder for callers to record their messages.

Patience and repetition are primary in making communication easier. Memory-impaired persons need more time to comprehend a message.

Present only one idea, question, or statement at a time. If necessary, repeat the question or statement exactly as you did before.

Speak slowly and clearly. Allow the person time to process information and respond. Talk about concrete (real) actions and objects. Demented persons lose the ability to deal with abstract concepts such as planning for the future.

Before asking a person to do something, address him or her by name to get his/her attention. Use short sentences, familiar words, and names or nouns instead of pronouns ("Fred is coming today," not "He is coming today").

Use positive statements. It's easier for memory-impaired persons to understand what you *want* them to do than what you *don't want* them to do. For example, say "Stay in the house" rather than "Don't go outside."

Statements with "extra" words frequently help the person grasp what you are saying. "Pick up your glass on the table" is preferable to "Pick up your glass" because it gives the person more specific information and may help him/her to focus actions.

Use eye contact when speaking to the person. Gestures and visual aids help communicate to the person what you want done. Using objects such as a comb or toothbrush will help identify activities. Pictures also may help convey ideas to the person.

Keep questions simple. For example, ask one-part questions like "Do you want tea?" Avoid open-ended questions like "What do you want to drink?" and multiple-choice questions ("Do you want tea or coffee, and do you want it now or with dessert?"). Such questions add to confusion and stress.

Ask questions that your patient can answer with "Yes," "No," or a gesture. Eventually, even questions requiring only a "Yes" or "No" response are difficult for some persons. "Here's your fruit" may be preferable to "Do you want some fruit?"

Reduce environmental noise, activity, and distractions. Correct sensory losses if possible. Use touch. It can be soothing and reduce feelings of isolation and rejection.

Touch can be a particularly important way of communicating with the person who no longer comprehends speech. Holding hands, hugging, giving a massage, or providing personal care such as combing the hair can communicate warmth and affection.

However, recognize that each person has a different level of comfort with touch and that sometimes the meaning of your touch may be misinterpreted. The need for touch must be met on an individual basis.

Many memory-impaired persons are able, on request, to give others a hug, massage, or back rub. They generally enjoy the closeness as well as the sense of success and giving that comes from such simple and appreciated tasks.

When the memory-impaired person is no longer able to communicate verbally, be sensitive to nonverbal behavior—facial expressions, tone of voice, body position, and eyes.

Try to respond to the person on a feeling level. Although memory-impaired people may not be able to communicate verbally, their feelings largely remain intact. Their behavior always has meaning, although *we* may not understand it.

Summary

A time may come when the personal care and safety needs of the impaired person exceed the resources and abilities of the most dedicated caregiver. Nursing home placement may be the next logical step.

Families facing this difficult decision must realize they have not failed, not broken a promise, not abandoned a loved one. They have only given up the physical chores of daily care.

As one nursing home administrator said, "Anyone can give a bed bath or help a person to dress, but only a family member knows the favorite treats, events, and memories that are meaningful to the person."

Resources

Alzheimer's Disease: A Family Information Manual, Mental Health Division, Canada, 1982.

Alzheimer's and Related Disorders Association, 70 East Lake Street, Chicago, IL 60601.

Mace, Nancy L. and Rabins, Peter V. *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life*, The John Hopkins University, 1982.

McDowell, Fletcher H. and Lincoln, Elizabeth M. (Eds.) *Managing the Person with Intellectual Loss at Home*. White Plains, N.Y.: Burke Rehabilitation Center, 1980.